



The Patient's Voice: Children's empowerment

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International CHI Conference

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Stella Promussas

- Born in 1999
- Congenital Hyperinsulinism
- genet. determined
- First year of life spent in hospital, with a few breaks



Weggelegt Kinder ohne Medizin



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» Czernin Verlag

Why do we need Lobby4kids?

- Children still don't get the importance they need
- They are not able to speak for themselves
- Life is still more difficult for children with disabilities and chronic diseases
- Deficiencies in health systems appear in a special way in these children
- Parents are overburdened with management and caring

Forming the association in 2005

Neutral society of
concerned families,
organisations, self
help groups and
doctors

The logo for 'Lobby 4 Kids' is displayed in a white rectangular box. The text 'Lobby' and 'Kids' is written in a blue, cursive font. A red heart shape is drawn around the number '4', which is also in a blue, cursive font. The heart and the number '4' are intertwined, with the heart's outline passing through the number.

Aims of Lobby4kids

Medicine:

- National healthplan
- Improvement of medical care of children with chronic diseases or disabilities
- Teams of emergency pediatricians all over Austria
- Nationwide mobile home nursing for free
- Establishment of departments for rare diseases

Aims of Lobby4kids

Social area:

- No patient's contribution for receipts or hospital stayings for children
- Expertise for ailments via pediatricians or nurses
- Financial securing of needed resources for children's hospitals or medical centers
- Plans for improvement of socially disadvantaged families

Aims of Lobby4kids

Social policy and law:

- sensibilising the public for a children's lobby
- Implementing patient's rights especially for children and adolescents
- Establishment of a patient's lawyer for children in every province
- Crosslinking and integration of all initiatives advancing children's health



Some members of Lobby4kids



Lobby4kids, CHI international and
Kongenitaler Hyperinsulinismus e.V are partners!!



Aims of Lobby4kids

Ethics:

- Public acceptance of the EACH – Charta (European Association for Children in Hospital) and its realisation in hospitals
- All these topics for children with disabilities and chronic diseases are of course CHI topics!!

EACH Charta

- Children shall be admitted to hospital only if the care they acquire cannot be equally well provided at home or on a day base.
- Children in hospital shall have the right to have their parents or parent substitute with them at all times.



Activities of Lobby4kids

- „Internet quick support“:
 - Problem of concerned family
 - E-Mail to Lobby's network
 - Solution within 48 hours
- Individual case support
- Public relations

Lobby4kids Database



KI(N)D SEIN
DABEI SEIN!



Dieses Projekt wird vom BM
für Gesundheit gefördert.



Problem „Inclusive Education“

- Children with chronic diseases and disabilities are entitled to be integrated and to get „inclusive education“ – this starts at the kindergarten
- Problem: In Austria no legal claim to kindergarten or after school care club
- Principle of voluntariness, Paragraph 50 medical law

Problems in practical experiences

- Children with PEG - tubes don't get anything to drink because nobody wants to touch the tube – also a CHI problem!
- Single parents get into poverty trap
- Children don't get real integration
- Far too little places for children with disabilities at the kindergarten

Lobby4kids Dreamteam



Some achievements of last years

- Forming public consciousness for disabled children
- Negotiations with urban administrations resulted in additional budget for hours of support and caring
- Topics of children with chronic diseases are more present in media

Next „TO DO´S“ Lobby4kids

- Support and caring for children with disabilities at schools, kindergarten and after school clubs have to be improved – we keep on fighting
- „Inclusive Education“ has to be attended by concerned families
- Gaps within the supplementary network of supplies (e.g. places on a treatment programme) have to be closed

Freshest I

- Elections in Austria September 29th: Statement of Lobby4kids for draft law for public school health – up to now no mentioning of children with disabilities
- Video campaign „Fit and strong“ of the Main Association of Austrian National Insurance with Stella and Irene and other Lobby4kids families: Challenge yourself – jeden Tag <https://youtube/cC7eb5sdY80>

Freshest II

- Transition Workshops on the symposium of the Liga for children's and young adult's health
- Trainings for school doctors in inclusion of children with disabilities and chronic diseases

Visit our Homepages!!

Lobby  Kids



www.lobby4kids.at

www.hyperinsulinismus.de

www.congenitalhi.org

Thank you for your attention!

